

HIV Reporting Frequently Asked Questions (FAQ)

Q: Why is it necessary to report HIV cases by name in California?

A: Without name-based HIV reporting, California will lose up to \$50 million annually in funding for services for people infected with HIV. It is necessary to report HIV cases by name to ensure that California remains competitive for Ryan White CARE Act (RWCA) funding. The RWCA provides funding for health care and support services for people infected with HIV. In previous years, RWCA funding was distributed based on the number of AIDS cases reported to the Centers for Disease Control and Prevention (CDC).

Beginning in 2007, RWCA funding will be allocated based on the number of both HIV and AIDS cases. Before HIV case counts can be included for RWCA funding, HIV case reports must first be accepted by the CDC. The CDC only accepts HIV and AIDS case data from states that report by name.

Q: Has California ever reported HIV by name?

A: No. HIV has only been reported in California by non-name code. California has maintained a secure name-based system for reporting AIDS cases for over 20 years. HIV reporting by non-name code was implemented in California in July 2002 and ended with the introduction of HIV reporting by name.

Q: How are HIV cases in California reported?

A: In California, both health care providers and laboratories report HIV positive test results to the local health department (LHD).

When a health care provider receives a patient's positive HIV test result from a laboratory, the health care provider submits an HIV case report form to the LHD. The HIV case report form contains the patient's name, date of birth, gender, social security number and clinical and demographic information. The laboratory that performs the HIV test submits the confirmed positive HIV test results, patient's name, birth, and gender, and the name of the patient's health care provider to the LHD where the health care provider's facility is located.

LHDs match HIV case reports from health care providers to reports from laboratories then send HIV case data to the California Department of Health Services (DHS), Office of AIDS (OA) HIV/AIDS Case Registry. Registry staff reviews HIV case reports from California's 61 health departments to ensure that statewide HIV information is accurate and complete. The OA Registry then submits HIV case data, **without names or other personal identifiers** to CDC

Q: When will health care providers and laboratories be required to start reporting HIV cases by name?

A: SB 699 (Soto), which requires health care providers and laboratories to report HIV infections by name to the local health department, was passed as an urgency measure. Governor Schwarzenegger signed SB 699 into law on April 17, 2006. Therefore, health care providers and laboratories must begin reporting HIV cases by name immediately, effective April 17, 2006.

Q: Who is required to report HIV cases?

A: Health care providers, laboratories, and local health departments are required to report cases of HIV infection.

Q: How are HIV data including names of HIV positive individuals transmitted from health care providers and laboratories to local health departments?

A: Healthcare providers submit HIV data on confidential case report forms to the LHD. Health care providers must ensure that patient confidentiality is maintained when reporting HIV cases to the LHD.

Office of AIDS provides technical guidance to LHDs, health care providers, and laboratories to ensure that confidential information is not exchanged through email, fax, or other non-secure methods. HIV case reports can be sent by traceable mail or courier services. Emergency regulations currently being developed by DHS will specify secure data transfer methods to be used by health care providers, laboratories, and LHDs.

Q: How are HIV and AIDS case data transmitted to DHS?

A: Methods for transmitting HIV and AIDS case data to DHS are established in the California Code of Regulations (CCR). In July 2002, upon implementation of HIV reporting by non-name code, DHS adopted regulations requiring LHDs to transfer HIV and AIDS case data to DHS by traceable mail. Emergency regulations currently being developed by DHS to implement HIV reporting by name will also specify secure data transfer methods to be used to transfer HIV and AIDS case data to DHS.

Q. What are the penalties for unlawfully disclosing HIV/AIDS information?

A: All HIV/AIDS case reports and any information collected or maintained in the course of HIV reporting that may directly or indirectly identify an individual are considered *confidential public health record(s)* under California Health and Safety Code (HSC) Section 121035(c) and must be handled with the utmost confidentiality.

Disclosure of identifying information from confidential public health records is only permitted if a specific exception is provided in statute. Unauthorized disclosure of confidential public health records is subject to civil penalties under HSC 121025(e).

- Negligent disclosure of information contained in a confidential public health record is subject to a civil penalty of up to \$2,500 plus court costs under HSC 121025(e)(1).
- Willful or malicious disclosure of the content of a public health record is punishable by a civil penalty of \$5,000-\$10,000 plus court costs under HSC 121025(e)(2).

- Willful, malicious, or negligent disclosure of information contained in a public health record that results in economic, bodily, or psychological harm to the person named in the record is a misdemeanor, subject to imprisonment for a period of up to one year and/or a fine of up to \$25,000 plus court costs under 121025(e)(3).

In addition, a person guilty of any disclosure described above that results in economic, bodily, or psychological harm to the person whose record was disclosed is personally liable for actual damages under HSC 121025(e)(4). Under HSC 121025(e)(5), each disclosure in violation of California law is a separate, actionable offense.

Q: How can the public be assured that HIV/AIDS information reported to OA will be kept confidential?

A: The HIV/AIDS Case Registry has been collecting AIDS case information including names for more than 20 years and has never had a breach of confidentiality. The HIV/AIDS Case Registry is housed inside a secure, locked room with restricted access. Electronic information stored in the HIV/AIDS Reporting System (HARS) is maintained on a stand-alone file server located in the locked Registry room. Computers used to operate HARS or containing confidential information are not connected to the Internet and are not accessible to unauthorized persons.

Q. When does the law permit disclosure of HIV test results?

A: The confidentiality of HIV results is specifically protected by California law, which prohibits unauthorized disclosure. California HSC 120980 requires that health care providers obtain a patient's written authorization before HIV test results are disclosed in an identifying manner. Disclosure is only permitted if a specific exception is provided in statute.

Disclosure to the person who is the subject of the HIV test or to that person's legal representative is not considered a disclosure under HSC 120980. HSC 121010 permits disclosure without prior authorization to:

- the individual who is the subject of the HIV test or his/her legal representative;
- health care provider(s) providing direct care and treatment;
- health care provider(s) involved in the receipt, processing, use and distribution of anatomical gifts;
- the designated officer of an emergency response employee and from that designated officer to the employee regarding possible exposure to HIV.

Inclusion of a person's HIV test results in his/her medical record is also not considered a disclosure under HSC 120980. HSC 120985 permits a physician who orders an HIV test to record the results in the patient's medical record, or otherwise disclose it without

written authorization to the patient's health care providers for the purpose of diagnosis, care, or treatment. Disclosure is permitted for the purposes of disease reporting and control by state and local public health agencies under subdivision (f) of HSC 121022.

Disclosure is also permitted in specific situations involving testing of incarcerated individuals described in Title 8 of the Penal Code under HSC 121000.

HSC 121015 allows health care providers to disclose a positive HIV test result to the local health officer, spouse, or other person reasonably believed to have been exposed to HIV. However, the healthcare provider may not disclose the identity of the individual whose positive HIV test prompted the contact.

Q: Is anonymous HIV testing still available?

A: Yes. California law preserves the ability of individuals to learn their HIV status through anonymous testing.